

## **Why Most Families of Training Center Residents Support Training Center Care**

The families of Virginia's training center residents recognize the need for more community options for people with intellectual disabilities (ID) and developmental disabilities (DD). At the same time, surveys consistently show that most training center families favor continuing center care for their relatives. We strongly believe this is not an either/or matter; rather, Virginia can afford and should offer a continuum of quality residential options for people with ID/DD. Then these individuals or, where appropriate, their legal representatives can choose the option that is best for them. This paper summarizes why most training center families favor continued center care for their loved ones in centers that are "right-sized" to reflect the lower census and modernized for efficiency. Separate papers will explain how the training centers help people in the community and why continuation of training centers does not jeopardize placements for people on the urgent ID or DD waiting lists.

**Who are the training center residents?** Currently, training centers offer specialized services uniquely tailored to the needs of many of the State's most disabled citizens, those with ID complicated by medical fragility or behavioral challenges. According to the latest University of Minnesota data (2010), 68% of Training Center residents had a diagnosis of profound ID and 62% had two or more of the following conditions: blind, cerebral palsy, epilepsy, psychiatric disorder, behavioral disorder or autism spectrum disorder. Among the most significant functional limits, 58% or more had limitations with regard to dressing, eating and toileting, and cannot communicate their desires verbally.<sup>1</sup> As of January of this year, for example, only two of CVTC's residents had fewer than two diagnoses in addition to ID.

Several factors have led to a concentration of citizens with complex disabilities. The availability of far more community options contributed to a long-term decline of 88% in the census since the early 1970s, from roughly 5,000 to 622, as of May 29, 2014. Also contributing were a changing national philosophy about care, the State's long-term efforts to discourage center placements, and the recent initiative to close four of the five centers. Meanwhile, the centers have accepted and successfully supported many who had failed to be adequately supported in even the best available community placements. With subsequent discharges since 2010, one would today expect an even higher percentage of center residents to have a diagnosis of profound ID as well as other complex conditions. In other words, those most capable of benefitting from the ability to make choices in the community have already moved there, leaving those requiring the greatest supervision for their health and safety in the training centers.

**What the families see as the benefits of training centers for their loved ones.** The families of training center residents are just like the families of people with ID and DD who live in the

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<sup>1</sup> Sheryl Larson, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010, *Research and Training Institute on Community Living*, University of Minnesota, 2012.

community. Most love their relatives deeply, visit often, take their loved ones out when feasible, and advocate for their welfare. The main reason most favor continued care in the centers is because they see the centers as offering stable, high quality, and often unique services to ensure the health and safety of the residents. They also see greater stability and coverage for needed services in the single comprehensive Medicaid funding source for Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), as opposed to the more limited, less assured funding for the Medicaid Home and Community-Based Services (HCBS) Waiver program, which covers people with ID/DD in the community.

*Quality of services for health, safety and community integration.* Training centers are financed through the Medicaid ICF/IID program, which provides funding for all needs identified by medical professionals. Stable funding sustains careers for direct support staff, many of whom have worked with the residents for decades, as well as health professionals with ID/DD specialization. The result is that the residents get what they need, whether it is dental services, constant medical and nursing care, physical and occupational therapy, or other specialized care. Stable living wages mean less turnover and more experienced staff, which is critical to the proper care of nonverbal people whose communication skills are very limited and subtle. It is also critical to proactive preventive care that can reduce the need for hospitalizations. Also, more staff eyes make it easier to monitor for errors, abuse and neglect.

Other unique supports at centers include a five-star dual certified nursing/skilled nursing unit at CVTC and an Observation Care Unit at NVTC that reduce the need for costly time in a hospital. Extensive safe spaces with controllable levels of stimulation are available for those who need it, such as individuals with pica who otherwise would ingest nonedible items or individuals with easily triggered behavioral problems, while others receive additional stimulation in a specially equipped sensory stimulation room or through on-campus therapeutic recreational activities.

In addition to the services provided through the ICF/IID program, training center families have engaged in ongoing fundraising efforts that have led to such enhancements as therapeutic pools, gymnasiums, nature trails, all-weather sports courts and pavilions. Families, in conjunction with their training center staff, have also recruited hundreds of volunteers who, for example, accompany residents on trips, assist with group activities such as Sunday church services, and visit residents to enrich their lives. At CVTC, for example, a great number of community organizations participate in the volunteer program, both onsite and off, including Liberty University, Lynchburg College and 60 local churches of all denominations.

Residents also go out into the community regularly. At NVTC, for example, roughly half of the residents historically have gone to off campus day programs; most of the others have on campus programs. Staff flexibility, through economies of scale, also offers greater participation for residents in off-campus activities, such as ball games, apple picking, concerts and other events.

Given the level of disability of training center residents and the many activities they participate in, either inside or outside of the facilities, most families believe the training centers are the most integrated setting for their loved ones.

This view is consistent with *Olmstead*. There, Justice Ginsburg carefully balanced the twin mandates of the ADA – to encourage the maximum community integration of individuals with ID while protecting the right to choice. On the one hand, she wrote that, in the ADA, “Congress explicitly identified unjustified ‘segregation’ of persons with disabilities [in institutions] as a ‘for[m] of discrimination’ that violates Title II of the Americans with Disabilities Act.” *Olmstead* at p. 2187. On the other hand, she also wrote that, under the ADA, there is no “federal requirement that community-based treatment be imposed on patients who do not desire it.” *Olmstead* at p. 2188. Particularly relevant to the environment provided by today’s training centers, as just discussed, was her recognition that, “Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, on a case-by-case basis, that setting may be an institution.” *Olmstead* at p. 2189.

*Stable and integrated supports.* Training center families appreciate the simplicity of the assured funding of needed services through the ICF/IID program. By contrast, families using the HCBS program face a system that does not provide as comprehensive benefits as the ICF/IID program. They must look to other parts of Medicaid for such services as medical and hospitalization. They also must seek additional supports, from CSBs and other programs, for important services that are not covered by Medicaid or that are not covered or capped by the waiver program.

Even if one can work one’s way through the maze of funding sources to meet most of the individual’s needs in the community, that is not the end of the process. Families in the community also must cope with Virginia’s inconsistent year-to-year fiscal commitments for community supports. Virginia has long lagged behind other states in funding for people with ID, now ranking 49<sup>th</sup> in the country. The result has been years of a waiver program with inadequate funding for services – for example, seven years without any increase in direct care wages, and, recently, cutting ID waiver slots back to only those legally required by the Settlement Agreement. Families thus share a healthy and rational skepticism as to whether the new waiver being considered will be generous enough to meet the needs of their loved ones with complex needs, and, even if it is, whether it will be adequately funded now and in the future.

In short, given the present better quality of services and assurance of a single dependable funding source for needed services under the ICF/IID program, it is not surprising that many training center families favor ongoing center care over the vagaries of the HCBS waiver program. They view the training centers as the best way to assure the continuity and quality of support for the wellbeing of their loved ones with complex needs. This sentiment is particularly true for the many elderly parents who want this assurance of high quality intensive training center care after they are gone.